

# Senate Study Bill 3122 - Introduced

SENATE FILE \_\_\_\_\_  
BY (PROPOSED COMMITTEE ON  
HUMAN RESOURCES BILL BY  
CHAIRPERSON EDLER)

## A BILL FOR

1 An Act relating to the newborn screening.

2 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

1     Section 1. Section 136A.2, Code 2022, is amended by adding  
2 the following new subsection:

3     NEW SUBSECTION. 1A. *“Congenital and inherited disorders*  
4 *advisory committee”* or *“advisory committee”* means the congenital  
5 and inherited disorders advisory committee created in this  
6 chapter.

7     Sec. 2. NEW SECTION. 136A.3A **Congenital and inherited**  
8 **disorders advisory committee established — process for addition**  
9 **of conditions to newborn screening.**

10     1. A congenital and inherited disorders advisory committee  
11 is established to assist the center for congenital and  
12 inherited disorders and the department in the development of  
13 programs that ensure the availability and access to quality  
14 genetic and genomic health care services for all Iowans.

15     2. The members of the advisory committee shall be appointed  
16 by the director and shall include persons with relevant  
17 expertise and interest including parent representatives.

18     3. The advisory committee shall assist the center for  
19 congenital and inherited disorders and the department in  
20 designating the conditions to be included in the newborn  
21 screening and in regularly evaluating the effectiveness and  
22 appropriateness of the newborn screening.

23     4. Within twelve months of the addition of a new condition  
24 to the federal recommended uniform screening panel, the  
25 advisory committee shall consider and make a recommendation  
26 to the department regarding inclusion of the new condition in  
27 the newborn screening, including the current newborn screening  
28 capacity to screen for the new condition and the resources  
29 necessary to screen for the new condition going forward.

30 If the advisory committee recommends inclusion of a new  
31 condition, the department shall include the new condition in  
32 the newborn screening within eighteen months of receipt of the  
33 recommendation, subject to the provision of necessary newborn  
34 screening capacity and resources.

35     5. The department shall submit a status report to the

1 general assembly, annually, by December 31, regarding all of  
2 the following:

3     *a.* The current conditions included in the newborn screening.

4     *b.* Any new conditions currently under consideration or  
5 recommended by the advisory committee for inclusion in the  
6 newborn screening.

7     *c.* Any new conditions considered but not recommended by the  
8 advisory committee in the prior twelve-month period and the  
9 reason for not recommending any such conditions.

10    *d.* Any departmental request for additional program capacity  
11 or resources necessitated by the inclusion of a recommended new  
12 condition in the newborn screening.

13    *e.* Any delay and the reason for the delay by the advisory  
14 committee in complying with the specified twelve-month time  
15 frame in considering or recommending the inclusion of a new  
16 condition in the newborn screening to the department.

17    *f.* Any delay and the reason for the delay by the department  
18 in complying with the specified eighteen-month time frame in  
19 including a new condition in the newborn screening following  
20 receipt of a recommendation from the advisory committee  
21 recommending the inclusion of such condition.

22    Sec. 3. Section 136A.5, Code 2022, is amended to read as  
23 follows:

24    **136A.5 Newborn ~~metabolic~~ screening.**

25    1. All newborns born in this state shall be screened for  
26 congenital and inherited disorders in accordance with rules  
27 adopted by the department.

28    2. An attending health care provider shall ensure that every  
29 newborn under the provider's care is screened for congenital  
30 and inherited disorders in accordance with rules adopted by the  
31 department.

32    3. **This section** does not apply if a parent objects to  
33 the screening. If a parent objects to the screening of a  
34 newborn, the attending health care provider shall document the  
35 refusal in the newborn's medical record and shall obtain a

1 written refusal from the parent and report the refusal to the  
2 department as provided by rule of the department.

3 Sec. 4. Section 136A.5A, subsections 1 and 4, Code 2022, are  
4 amended to read as follows:

5 1. Each newborn born in this state shall receive a critical  
6 congenital heart disease screening by pulse oximetry or other  
7 means as determined by rule, in conjunction with the ~~metabolic~~  
8 newborn screening required pursuant to [section 136A.5](#).

9 4. Notwithstanding any provision to the contrary, the  
10 results of each newborn's critical congenital heart disease  
11 screening shall only be reported in a manner consistent with  
12 the reporting of the results of ~~metabolic~~ newborn screenings  
13 pursuant to [section 136A.5](#) if funding is available for  
14 implementation of the reporting requirement.

15 EXPLANATION

16 The inclusion of this explanation does not constitute agreement with  
17 the explanation's substance by the members of the general assembly.

18 This bill relates to newborn screenings.

19 The bill establishes, in Code, the congenital and inherited  
20 disorders advisory committee (advisory committee), which  
21 currently is established in administrative rules. The bill  
22 provides, as is provided in administrative rules, that the  
23 advisory committee is established to assist the center for  
24 congenital and inherited disorders (center) and the department  
25 of public health (DPH) in matters relating to genetic  
26 and genomic health care services for all Iowans, that the  
27 members of the advisory committee shall be appointed by the  
28 director of public health, that the members shall include  
29 persons with relevant expertise and interest including parent  
30 representatives, and that one of the duties of the advisory  
31 committee is to assist the center and DPH in designating the  
32 conditions to be included in the newborn screening and in  
33 regularly evaluating the effectiveness and appropriateness of  
34 the newborn screening.

35 The bill specifically requires that within 12 months of the

1 addition of a new condition to the federal recommended uniform  
2 screening panel, the advisory committee shall consider and  
3 make a recommendation to DPH regarding inclusion of the new  
4 condition in the newborn screening, including current newborn  
5 screening capacity to screen for the new condition and the  
6 resources necessary to screen for the new condition going  
7 forward. If the advisory committee recommends inclusion of  
8 a new condition, DPH shall ensure that the new condition is  
9 included in the newborn screening within 18 months of receipt  
10 of the recommendation, subject to the provision of necessary  
11 newborn screening capacity and resources.

12     The bill requires DPH to submit an annual report to the  
13 general assembly by December 31, regarding the current  
14 conditions included in the newborn screening, any new  
15 conditions currently under consideration or recommended by the  
16 advisory committee for inclusion in the newborn screening, any  
17 new conditions considered but not recommended by the advisory  
18 committee in the prior 12-month period and the reason for not  
19 recommending any such conditions, any departmental request for  
20 additional newborn screening program capacity or resources  
21 necessitated by the inclusion of a recommended new condition  
22 in the newborn screening, and any delay and the reason for  
23 the delay by the advisory committee or DPH in complying with  
24 the specified time frames for considering and recommending or  
25 adding a new condition to the newborn screening.

26     The bill also changes references to "newborn metabolic  
27 screening" or "metabolic newborn screening" to "newborn  
28 screening".